

or cow's milk-based formula until more tests are done. The health care provider will tell the parents if their baby needs to switch to soy-based formula.

As the baby begins to eat solid foods, the parents will have to be careful about which foods are given to the baby. The baby must not eat foods that contain **any** milk or dairy products, including all animals' milk like goat's milk. The baby's doctor will usually refer the parents to a registered dietitian (RD) to help them learn how to manage their baby's diet.

Following the diet very strictly will give a baby with galactosemia the best chance to grow up healthy.

For more information, please contact:
South Carolina Department of Health
and Environmental Control
Division of Women and
Children's Services
Box 101106
Columbia, SC 29211
(803) 898-0767
or
your county health department

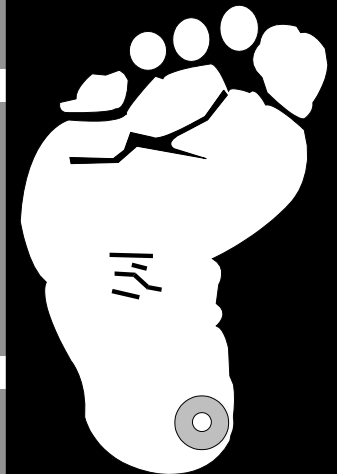


Division of Women and Children's Services

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NEWBORN SCREENING

For
Your
Baby's
Health




What You Should Know
When a Second Test for
Galactosemia Is Needed



Newborn Screening

A small sample of your baby's blood was collected soon after birth and was sent to the DHEC laboratory for testing. This testing is called Newborn Screening. In SC, newborns are tested for several genetic and chemical disorders. These disorders include Phenylketonuria (called PKU), Congenital Hypothyroidism, Galactosemia, Congenital Adrenal Hyperplasia (called CAH), Medium Chain Acyl Co-A Dehydrogenase Deficiency (called MCADD), and Hemoglobinopathies. In some cases, a second test is needed to help your doctor decide if your baby has one of these disorders. In many cases, the second test will be normal. However, if your baby does have one of the newborn screening disorders, early treatment will give him or her the best chance to grow up healthy.




Galactosemia

Your baby's first test showed that he or she could possibly have Galactosemia. Here's a brief description of Galactosemia and how it is treated.

Galactosemia is a genetic disorder that is found in around one of every 70,000 babies born each year. When a baby has galactosemia, he or she cannot break down galactose, a part of the sugar lactose that is found in breast milk and cow's milk-based infant formula.

Galactose builds up in the baby's blood and damages the baby's body. The baby can have serious health problems like a swollen liver, kidney failure, brain damage, and cataracts in the eyes. There is a 70 percent chance that a baby with galactosemia will die if he or she is not treated.

Newborn screening allows the



baby's doctor to tell if the baby probably has galactosemia before he or she gets sick. This lets the doctor give the parents special instructions on how to keep the baby from getting very sick from galactosemia.

Most newborn babies drink either breast milk or cow's milk-based formula as their main "food." A newborn baby with galactosemia must not drink breast milk or cow's milk-based formula because both contain galactose. The safest "food" for a newborn baby with galactosemia is soy-based formula.

In some cases, the baby who needs a second test for galactosemia will need to switch from breast milk or cow's milk-based formula to soy-based formula before the doctor knows for sure that the baby has galactosemia. In other cases the baby can continue on breast milk